

“It’s hard to ask...”

Merryn Jones
Transplant Coordinator



What this presentation will cover

- ▶ Summary of research findings – “It’s hard to ask”
- ▶ Why this is important – the big picture



Findings



Patients may approach some family members and not others, based on preconceptions or misinformation



Almost half of those patients eligible for transplant had not approached anyone at all

Snapshot quotes...

"Who would I ask? All my whanau (family) are sick"

"I don't want to do that to my kids.
And plus, they've got kids.
So they've still got a life to live"

"Some of them, you know it's all drunk talk, and I don't take no notice of that"

"I wouldn't be able to cope if something happened to her"

"No-one's offered...like I'm from a family of nine, and none of them have offered me a kidney. So if they're not gonna offer, I'm sure as heck not gonna ask"

"How can I ask for a kidney, when I can't even ask to borrow a chainsaw?"

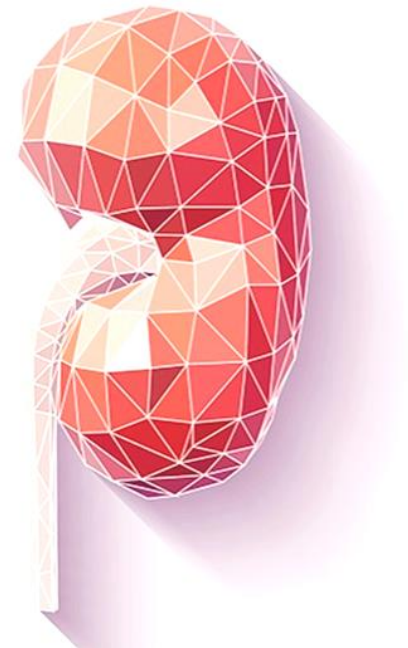
"It's a big pool, but a small net"

"If I'm gonna get well, I gotta get a kidney...I'll do a karakia (prayer) and make use of the new one"

"I've never felt comfortable to ask"

Results

- ✓ ***Being expected to recruit living kidney donors is a barrier in itself for many***
- ✓ Most recipients desired **more support**
- ✓ Most recipients are concerned for health & wellbeing of loved ones, **above their own need**
- ✓ Some have **limited recruitment opportunities, especially Māori and Pasifika**
- ✓ Some have **limited health literacy**
- ✓ Some have **poor self-efficacy**
- ✓ Many Māori favoured a **whanau approach** to recruitment



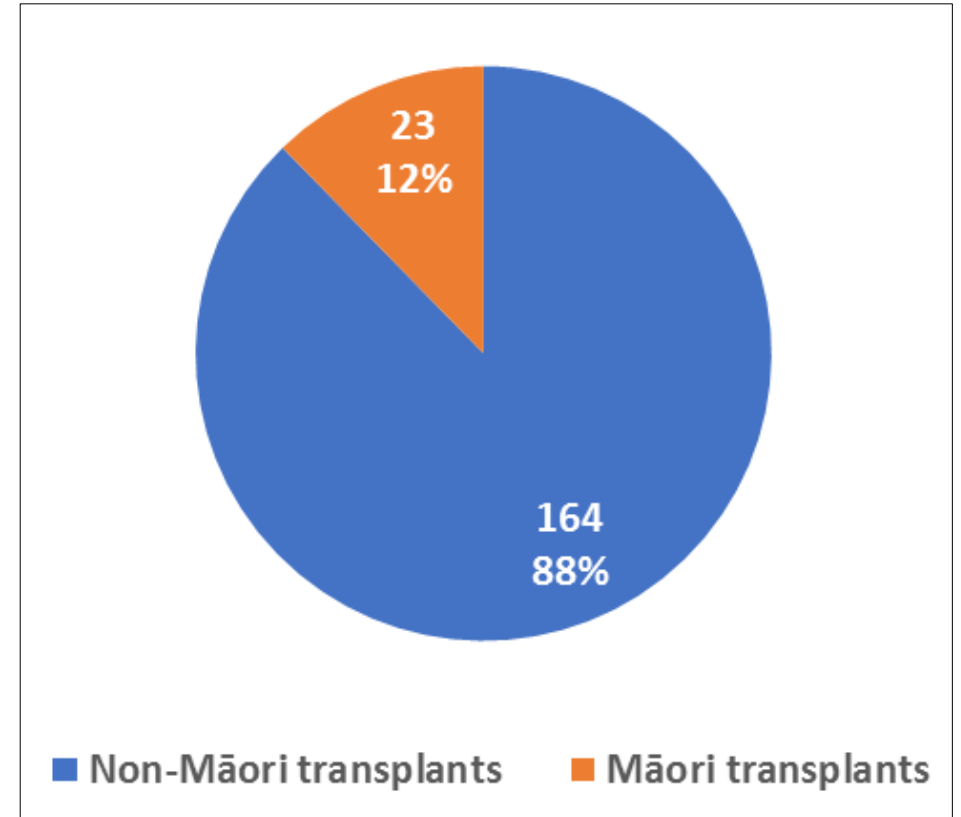
So why is this important?

ANZDATA (2018)

187 kidney transplants in 2017 in NZ:

- ◆ 118 DDL
- ◆ 69 LKD

23 of these identified as Māori (12.3%)



NZ Nephrology 12th Annual Report (2019)



- NZ European patients are 4-8 times more likely to receive a pre-emptive kidney transplant than non-European.
- Diabetes causes kidney failure in 74% of Pasifika patients and 68% of Māori patients, compared with 24% European patients in NZ.

Health Disparities



Compared with non-Māori, Māori have:

- ▶ 5 x higher rates of renal failure
- ▶ 3 x higher number of lower limb amputations
- ▶ 2 x higher rates of diabetes

Guyon Espiner, RNZ Website 28/5/2019

Potential practice and delivery changes

Psychosocial
screening and
support

Increased
conversations about
transplant

Improved health
literacy

Media campaigns

Involve whanau in
decision-making

Early referral to
renal services

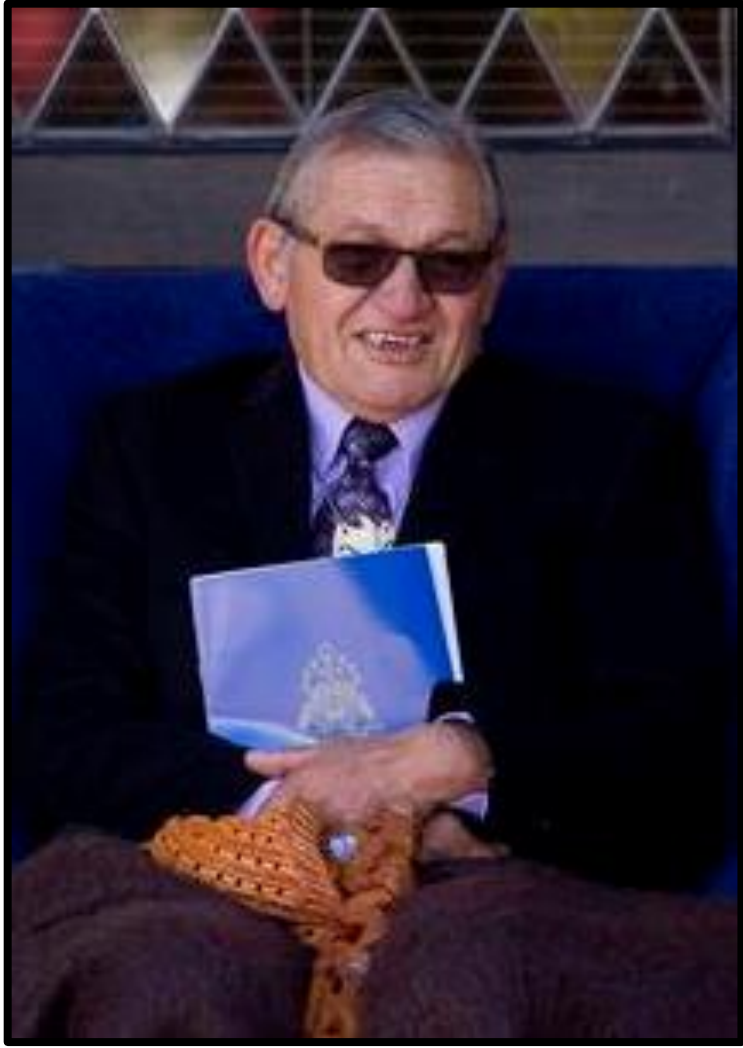
Shared decision making

“Kidney disease is quiet”

So who can be a living kidney donor?

- Anyone can offer
- Don't have to be related
- Don't have to have same blood group
- Donor needs to be healthy
- Lots of tests (full warrant of fitness) to determine health
- Tests are completed over a period of months







Deceased organ donation



- For patients with limited recruitment opportunities, deceased kidney donation fulfils a need
- Poor understanding of the circumstances whereby organs could be harvested
- Education needed re: procurement of deceased organs in the event of accidental death or brain injury



